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Social and human rights questions: genetic privacy and non-discrimination

Information and comments received from Governments and relevant international organizations and functional commissions pursuant to Economic and Social Council resolution 2001/39

Report of the Secretary-General

Summary

In its decision 2003/232 of 22 July 2003, the Economic and Social Council decided to postpone consideration of the question of genetic privacy and non-discrimination to its substantive session of 2004 to allow for a thorough review of the issue on the basis, inter alia, of the report of the Secretary-General requested by Council resolution 2001/39 of 26 July 2001, entitled "Genetic privacy and non-discrimination" (E/2003/91).

The present report contains further information and comments received from Member States and various entities of the United Nations system. This supplemental information has been compiled in an effort to provide the Council, at its substantive session of 2004, with a clearer picture of the views of Member States, and should be read in conjunction with the above-mentioned report.

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I. Introduction

1. The Economic and Social Council considered the issue of genetic privacy and non-discrimination at its substantive session in 2003. It had before it a report of the Secretary-General (E/2003/91) containing information and comments received from Member States and various entities of the United Nations system pursuant to Council resolution 2001/39 of 26 July 2001 entitled "Genetic privacy and non-discrimination".

2. In that resolution, the Council recognized and asserted the importance of the principle of non-discrimination on the basis of genetic characteristics. The Council urged States to ensure that this principle be respected and that genetic testing be done with the consent of the person concerned, while protecting his or her privacy. It also invited States to take appropriate specific measures to ensure respect for these principles, called upon them to promote the development and implementation of standards in this field and urged them to support research in the area of human genetics and biotechnology with due respect for the above-mentioned principles. It also requested the Secretary-General to bring resolution 2001/39 to the attention of all Governments and relevant international organizations and functional commissions in order to collect information and comments, and to submit a report thereon to the Council at its substantive session of 2003.

3. In its decision 2003/232, adopted at its substantive session of 2003, the Council decided to postpone consideration of the question of genetic privacy and non-discrimination to its substantive session in 2004 to allow for a thorough review of this matter. To assist the Council in this respect, a further request for information and comments on this issue was transmitted to Member States and various entities of the United Nations system. This report contains the supplemental information received.

II. Information and comments provided by Member States

Denmark

4. The Danish Medical Research Council and the Danish Social Science Research Council fully supports the resolution, which intends to bring to the attention of all Governments and international organizations the issue of genetic privacy and non-discrimination. The resolution deals with important issues in relation to genetic testing, stressing consent and confidentiality as prerequisites for the undertaking of such testing, as well as stressing that consent must be prior, free, informed and express. The resolution invites States to take measures to prevent that the use of genetic information lead to discrimination, particularly in social, medical and employment-related areas.

5. It is to be noted that Denmark has implemented legislation prohibiting the discriminatory use of genetic information relating to healthy subjects in the areas related to employment and insurance. Furthermore, clinical genetic testing is performed in specialized medical centres, and testing as part of research protocols requires the approval of a scientific ethical committee, ensuring that no testing is done without the subject's consent and that information pertaining to other members

of the subject's family is handled in a professional way respecting individual autonomy.

6. Denmark finds it very important that research in this area fully respects human dignity, freedom, and human rights, as stated in the resolution, and finds that this aim can best be realized through contributions from the social sciences and the humanities.

7. Furthermore, Denmark presumes that the resolution will be in conformity with the European Convention of 4 April 1997 concerning human rights and biomedicine, which Denmark has incorporated into its legislation by order number 65 of 11 December 2000.

Greece

8. Greece's National Bioethics Committee has already occupied itself specifically with the issue in its recommendation on the collection and use of genetic data (16 September 2002). This recommendation has the same scope as Council resolution 2001/39. Both texts underline, in particular, the pivotal role of the free consent of the person concerned for the use and processing of his/her genetic data.

9. In respect to individual issues referred to in Council resolution 2001/39, the Committee considers section 3, according to which States are called upon to take the appropriate measures, including legislative, for the prevention of genetic discrimination in sensitive social fields (including the field of work), in the private and public sectors, to be very important. The Committee also recognized in its recommendation the need for special legislation in the context of labour relations.

10. Section 4 of the resolution is also substantive. The Committee regards as necessary an addendum for the need of special legislation with respect to biobanks.

11. The Committee also draws attention to the importance of the control of the use of genetic information by personal data protection authorities, even if there is no relevant legislation thereon. It would be appropriate to emphasize the importance of such institutions in the resolution.

Iceland

A. Act on Biobanks

12. On 1 January 2001, the Icelandic Act on Biobanks entered into force. The Act covers the storage of biosamples in biobanks, but not temporary storage, that is, storage for the purposes of medical diagnosis or minor scientific research. The establishment of a biobank requires a licence, issued by the Minister of Health. Among the conditions for a licence are that the biobank will be kept physically in Iceland, that clear information is provided on the manner in which samples are to be stored and that the security assessment and procedures regarding the harvesting and processing of the biosamples are in compliance with rules, which the Data Protection Authority publishes on the security of personal data in biobanks. The Data Protection Authority is now evaluating the security of personal data in biobanks with regard to these rules.

13. The harvesting of a biosample for storing in a biobank requires informed, written consent by the biosample donor. On the other hand, storing of a biosample, which has been previously harvested for medical diagnosis purposes, requires only presumed consent. The biosample donor can at any time revoke his or her consent. If the biosample was collected for storage in a biobank, then revoking the consent requires the destruction of the sample. But if it was harvested for medical purposes, then revoking the presumed consent only constitutes a ban on the usage of the biosample except for the benefit of the donor or with his or her separate, express permission. However, if vital interests are at stake and the benefit outweighs the possible inconvenience for the biosample donor of other persons, the biosample may still be used for those purposes.

14. The purposes for which a biosample may be used are the clear and legitimate purposes for which it was collected; diagnosis of diseases; quality control, method development, and teaching purposes, as long as the biosamples are processed without personal identifiers; scientific research; and use for other purposes than those the samples were collected for if vital interests are at stake and the benefit outweighs the possible inconvenience for the biosample donor or other persons. For use of biosamples in scientific research and other purposes than those they were collected for, a permit from the Data Protection Authority and the National Bioethics Committee is needed (this overview of the Act on Biobanks is based on an unpublished description of the act from May 2003 by Hördur Helgi Helgason, consultant with The Legal Farm).

B. Act on a Health Sector Database

15. On 22 December 1998, the Act on a Health Sector Database entered into force. According to the Act, a centralized database (which has not yet become a reality) will contain data from medical records on the whole Icelandic population. The private company *deCODE/Íslensk erfoagreining* has been granted a licence by the Minister of Health to create and operate this database. According to the Act, it shall only contain "non-personally identifiable health data with the aim of increasing knowledge in order to improve health and health services". Those who do not want to have data from their health records recorded in the database have the right to abstain, but consent is not required. The health data may be joined with data from a database containing genetic data and a database containing genealogical data. The results of the joining of these three databases must be non-personally identifiable. The Data Protection Authority shall monitor the creation and operation of the health sector database and the joining of databases, but some tasks concerning the supervision of the database shall be undertaken by the Committee charged with the creation and operation of a health service database and an interdisciplinary ethics committee, which shall assess studies carried out within the licencee's company and research questions for the database which are received.

16. On 27 November 2003, the Supreme Court of Iceland delivered a judgement in a case concerning the health sector database. The circumstances in the case were as follows: A woman wanted information on her late father not to be put into the database, but she was denied of this since the act on the database only grants this right to the data subject himself. However, the Supreme Court came to the conclusion that her claim should be accepted because health information on her father could be relevant in assessing her own health. Also, in the light of the Constitution of Iceland, which grants everyone the right to privacy, the Supreme

Court considered the Act on the database to be too vague in terms of data security, e.g., encryption of data, and security when matching the data in the health sector database with data in the geneological database and the genetic database.

C. Informed consent in scientific research

17. Informed consent is often required for the use of genetic data in scientific research. According to the Act on Patient Rights, participation in scientific or medical research must be based on an informed consent. However, research projects that are completely retrospective may, according to the Data Protection Authority's interpretation, be performed without consent if there are some special circumstances justifying it, for example, if working with a very big sample of data subjects is unavoidable.

18. In permits issued by the Data Protection Authority for the processing of personal data in scientific research, informed consent is often required. Such processing need not always be based upon such a permit. However, according to rules on when to notify or obtain a permit for the processing of personal data, issued by the Data Protection Authority, a permit is always needed for genetic research. Whether or not the consent of the data subjects is required in such permits, depends, of course, on the legal considerations described above.

19. When informed consent from the data subject in scientific or medical research is required according to law, regulations or permits from the Data Protection Authority, the consent must be obtained in accordance with rules on how to obtain informed consent for the processing of personal data in scientific, medical research, issued by the Data Protection Authority. Among other things, those rules state that a participant must be informed in writing on, for example, the purpose of the project, how it will be conducted, possible dangers, the kinds of information that will be processed, wherefrom information will be sought, security of data, when personal information and personal identifiers will be destroyed, whether data will be transmitted abroad or published on the Internet, and whether a subject can revoke his or her consent and what implications that will have, among other things, on personal data that has been processed.

D. Act on a police genetic data register

20. On 31 May 2001, the Act on a police genetic data register, entered into force. By this Act, the National Commissioner of the Icelandic Police shall be in charge of a digital register containing genetic data. The register shall be used to facilitate the investigation of criminal cases. Genetic data may only be registered on persons that have committed certain severe crimes, such as murder, rape, battery, and sex-abuse of children, but also when there are "urgent reasons" and the information is of "special significance for the utility value of the register". The data subject shall be notified in writing of the registration. Data shall be obliterated no more than two years after the data subject has passed away, six months after he or she has been found innocent in a reopened case, or when it is discovered that the data is wrong or has been registered unlawfully. The processing of data shall be in conformance with the Act on the protection and processing of personal data, under the authority of the Data Protection Authority.

E. Bill on an act on insurance contracts

21. A bill on a new act on insurance contracts is now (February 2004) before the Icelandic Parliament. According to the bill, an insurance company may not, before or after an insurance agreement is made, seek, obtain by other means, receive, or exploit information on an individual's genetic characteristics. Also, it is prohibited for an insurance company to seek investigations that are necessary to gain access to such information. However, this prohibition does not apply to investigations of the current or former health status of the insurance taker or other individuals. The Data Protection Authority has criticized that investigations may be made on the health of "other individuals". It considers that such investigations cannot be anything else than investigations of genetic characteristics (contrary to the views that are expressed in the remarks in the bill on this clause).

Malaysia

22. Malaysia views the subject of genetic privacy and non-discrimination as one that inherently seeks to balance the advancement of science and technology while protecting the rights of individuals. Rapid progress and achievements in the area of biotechnology have allowed scientists and researchers to map the human genome, allowing for the greater advancement of knowledge concerning genetic and medical sciences. At the same time, there is a need to ensure that progress in this area does not infringe upon human rights, and human beings are not discriminated against based on their own genetic information. Moreover, the ethical and moral questions raised with regard to genetic information need to take into account the concerns and sensitivities of countries and communities and strike a balance between the needs of science and those of privacy.

23. Essentially, the issues involved in genetic privacy and non-discrimination revolve around, but are not limited to, the cloning of human beings, the disclosure of genetic and personal information, confidentiality of information between doctors, patients and the Government, the use of body parts from deceased persons for therapeutic purposes or for medical education and research, and discrimination based on genetic information. Malaysia believes that any measure to address these issues require the active participation of Governments in enacting and enforcing necessary legislation, as well as ensuring the primacy of and adherence to the country's laws. Towards this end, the Malaysian Government is taking necessary steps to address this issue.

24. At present, the Government of Malaysia is formulating legislation regarding the confidentiality of genetic information of the individual, thus setting the standard for the collection, use and disclosure of such information. The Ministry of Health is in the process of setting up the National Ethical Council to ensure consistency with regard to the ethical consideration of all aspects of research activities involving human subjects and to ensure the rights of its citizens, including the protection of their privacy in such studies.

25. Malaysia is considering amendments to specific legislation, as well as the enactment of new legislation to address the issues involved in genetic privacy and non-discrimination.

A. Human Reproductive Cloning Bill

26. The Government is considering a Human Reproductive Cloning Bill with the purpose of prohibiting the reproductive cloning of human beings, in particular addressing human reproductive cloning by somatic cell nuclear transfer and other methods that are to be determined. Provisions will be included to prohibit the disclosure of information to any person other than an authorized officer in the said exercise.

27. The Bill will also contain provisions on enforcement and penalties for contravention of the provisions of the Bill. Certain exemptions, however, will be provided in relation to the prohibition, among others, where disclosure is required for the purpose of legal proceedings, investigations and enforcement of relevant laws.

B. Personal Data Protection Bill

28. The Government is in the process of drafting a Personal Data Protection Bill, which aims at regulating the protection of personal data. Personal data is defined as information recorded in a document, whether automatically processed or manually recorded, which relates to a living individual and which is in the possession of an organization or public sector agency. The information may be contained in any document, including a disc, tape or other device. The information includes text, as well as visual images, such as photographs and film, and excludes oral information. This personal data can only be disclosed with the consent of the individual.

29. The Bill also provides certain exemptions where the information is required by law, by an order of the Court, to assist in legal proceedings and for research purposes. Results from research that utilizes the personal data of an individual shall not reveal the identity of the individual from whom the information was obtained.

30. The Bill also provides for the inclusion of genetic information in the definition of personal data to be specified as "sensitive personal data". The utilization of such data in collection, use and disclosure will be included in existing regulations such as the Private Health Facilities and Services Act 1998, section 115 (Confidentiality of Information).

31. Confidentiality between doctors and patients is addressed in the Medical Act 1971, section 29 (2)(b), which provides for disciplinary proceedings against registered medical practitioners in breach of professional conduct. This is based on the Code of Conduct of Professional Conduct, section 2: Abuse of professional privileges and skills (Abuse of trust and confidence). Doctors are expected to conform to the guidelines issued by the Malaysian Medical Council in carrying out their duties.

C. The Human Tissues Act 1974

32. The Act regulates the use of body part(s) (tissue) from deceased persons for therapeutic purposes and for the purposes of medical education and research. Section 2(2) of the Act provides for consultation with the next of kin to ensure that there has been no expressed objection by the deceased (when alive) to the removal of any body part(s) (tissue) from his body.

D. Persons with disabilities

33. The Government of Malaysia is drafting a bill on persons with disabilities, which would prohibit discrimination against such persons in both the public and private working sectors, education and other areas. Although the bill does not specifically provide for the non-discrimination against persons with disabilities based on their gene pool information, it does however provide for some protection against discrimination on such basis.

E. Other issues

34. Above and beyond specific legislation to safeguard human rights with respect to the issue of discrimination, the Malaysian Federal Constitution, under its article 8(1), guarantees equality for all persons before the law. Article 8(2) of the Constitution provides that there shall be no discrimination against citizens on the grounds of religion, race, descent, place of birth or gender in any law or in the appointment to any office or employment under a public authority. An individual's genetic information is therefore prohibited from being used in any form of discrimination, whether in social, medical or employment-related areas.

35. The Ethical Research Committee of the Ministry of Health does not allow genetic testing to be carried out on any specimen that is sent overseas or in any research where genetic testing is not included in the main objective. If there is a request to do so, consent has to be obtained from the trial subjects with the condition that they need to understand fully the implication of the tests being carried out.

36. Another important aspect of genetic privacy which needs to be addressed is the copyright issue with regard to genetic information. The existing and proposed legislations in Malaysia take into account this concern. However, the relative infancy of genetic information and non-discrimination issues require further study into this aspect.

Mali

37. The Government of Mali has provided the following communication from the permanent secretariat of the National Committee for Health and Life Science:

Considering the 1992 Constitution of Mali, which provides:

Article 1: "The human person is sacred and inviolable, and all individuals have the right to life, liberty, security and personal integrity";

Article 2: "All Malians are born and remain free and equal in their rights and duties. Any discrimination based on social origin, colour, language, race, gender, religion or political opinions is prohibited";

Article 6: "The home, property, private and family life, and privacy of correspondence and communications are inviolable";

Article 7: "Freedom of the press is recognized and guaranteed. It shall be exercised under conditions established by law";

Article 17: "Education, instruction, training, work, housing, leisure, health and social welfare constitute recognized rights";

Considering the African Charter on Human and Peoples' Rights, to which Mali has acceded, which provides, inter alia:

Article 1: "The Member States of the Organization of African Unity parties to the present Charter shall recognize the rights, duties and freedoms enshrined in this Charter and shall undertake to adopt legislative or other measures to give effect to them";

Article 2: "Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status";

Article 4: "Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right";

Considering the international conventions to which Mali has acceded:

(a) Universal Declaration of Human Rights:

Article 2: "Everyone is entitled to all the rights and freedoms set forth in this Declaration";

(b) Declaration of Helsinki of the World Medical Association:

Article 21: "Every precaution should be taken to respect the privacy of the subject, the confidentiality of the patient's information";

(c) International Code of Medical Ethics, adopted at the 35th World Medical Assembly at Venice (Italy) in October 1983, which stipulates in its "Duties of physicians in general": "A physician shall preserve absolute confidentiality on all he knows about his patient even after the patient has died";

Considering the present resolution which has been transmitted to us,

The permanent secretariat of the National Committee for Health and Life Science believes that the draft resolution fully accords with Mali's concerns and commends its authors for their efforts.

Mexico

38. The Federal Act on Transparency and Access to Public Government Information entered into force on 12 June 2002. Articles 13 and 18 thereof designate as classified any information which, if disseminated, could endanger the life, safety or health of any person, and as confidential any personal data which, pursuant to the Act, requires the consent of the individual concerned prior to its dissemination, distribution or sale. Similarly, article 21 of the Act provides that individuals subject to it may not disseminate, distribute or sell the personal data stored in information systems created by them in exercise of their functions, except in cases where they have obtained the explicit consent, in writing or by a similar means of authentication, of the individuals to whom the data refers.

39. Article 100 of the General Health Act sets out the guidelines to be followed when carrying out research into human beings. The last section of that article refers to additional guidelines contained in the regulation implementing the General Health Act in relation to health-related research, article 21 of which provides, inter alia, that individuals likely to be subjected to research must, prior to giving their consent, be informed that their identity will not be disclosed and that their personal information will remain confidential. Article 421 of the General Health Act provides that any person departing from the aforementioned guidelines shall receive an administrative sanction consisting of a fine of between 4,000 and 10,000 times the average minimum daily salary in the relevant economic sector.

40. Moreover, on 23 October 2003, with presidential assent, the National Commission for the Human Genome was established. The Commission is responsible for, inter alia, proposing any necessary amendments and updates to the relevant legal framework, recommending criteria to be observed during study and research involving the human genome and cooperating with the competent bodies in order to establish the ethical principles that must guide research and technological development relating to the human genome.

Oman

41. Genetic tests are performed with the consent of the individual and with the guarantee that information obtained from genetic tests will be confidential and not to be used against them, and not subject them to discrimination based on genetic characteristics, within the bounds of international law of human rights. Enormous progress has been achieved in the field of genetic research, which presents the opportunity to discover much more information regarding individual genetic characteristics when carrying out this type of test. It is, therefore, important to enact laws based on moral norms and general rules to deal with the results of these tests. It is necessary to review these laws periodically, to update them and to include provisions as required concerning genetic privacy, since genetic information could open the door to various types of discrimination.

42. The Sultanate of Oman does not discriminate based on genetic characteristics. Therefore, it does not carry out compulsory genetic tests.

Serbia and Montenegro

43. In the existing legislation that regulates the system of health-care and health insurance in the territory of the Republic of Serbia there are no specific provisions related to genetic data and non-discrimination. Article 12 of the Law on Health-Care Protection stipulates that "medical workers and other employees shall be obliged to keep professional secrets, i.e. to maintain the privacy of data on the health condition of patients, including the causes, circumstances and consequences of their illness. These data shall not be communicated to other persons or in any way made public that might reveal the identity of the patient."

44. Health-care institutions and other health-care providers, including medical personnel ensuring health care, shall be obliged to apply only tested and scientifically proven methods and procedures in the course of prevention, diagnosing and treatment of diseases and rehabilitation. New methods and

procedures in the provision of health care may be introduced with the prior approval of the relevant medical institution, on the basis of an opinion provided by the ministry in charge of health care and an appropriate medical university.

45. Health-care institutions in the territory of the Republic of Serbia that conduct genetic research with a view to facilitating early detection and diagnosis of genetic diseases are obliged to abide by the legal regulations mentioned above and respect the dignity and privacy of each patient. The importance of maintaining the privacy of genetic data and non-discrimination and of the recommendations and resolutions of the United Nations, World Health Organization and European Union in the field of human rights, and the need to promote health care and non-discrimination in the field of providing health-care protection were used as guidelines in drafting the new laws. For example, the draft Law on biomedically assisted insemination procedures regulates medical documentation related to this type of insemination and the characteristics of scientific and research procedures on reproduction cells and embryos, as well as respect for the general principles of medical ethics and patients' rights. Acknowledging that it is important to address appropriately the issue of the privacy of genetic data and principle of non-discrimination, the competent authorities in the Republic of Serbia continue with their efforts to enact legislation and create an appropriate institutional framework for its implementation.

46. In the Republic of Montenegro, under the existing Law on Health-Care Protection there are no legal provisions ensuring protection of genetic data and non-discrimination. The new law on health-care protection, whose adoption is pending, provides for the protection of patients' rights, in line with the provisions of the European Charter. There are plans to enact a law on the management of waste, which will regulate the issue of medical waste disposal.

Tunisia

47. All the provisions of the draft resolution on discrimination and genetic privacy are in line with the ethical principles that we have always defended within all international organizations, in particular the United Nations Educational, Scientific and Cultural Organization (UNESCO).

48. The National Medical Ethics Committee has always considered that all States should ensure that no one is subjected to discrimination based on genetic characteristics, that the privacy of those subject to genetic testing is protected and that genetic testing is done with the prior, free and informed consent of the individual or authorization obtained in accordance with domestic law or the international law of human rights.

49. In this regard, it should be pointed out that the Tunisian delegation, that participated in the work of the International Bioethics Committee from 23 to 27 June 2003 at UNESCO and chaired the meeting of government experts responsible for finalizing the draft international declaration on human genetic data, considered at length the two ethical principles mentioned in the aforementioned draft resolution and was able to formulate a consensus draft declaration that was adopted by the General Conference in September 2003. The draft declaration addressed the collection, processing, use and storage of human genetic data, which have potential risks for the exercise and observance of human dignity, human rights and fundamental freedoms.

50. Although research involving genetic data continues to raise great hopes in the international scientific community and civil society, who see in it the possibility of diagnosing and even treating and alleviating genetic diseases, it must be pointed out that diagnoses of genetic diseases have ethical implications and may compromise individuals' free will and privacy and give rise to new forms of stigmatization or even discrimination in the area of employment. Hence there is a need to prohibit by law discrimination based on genetic characteristics and to protect the right to confidentiality of individuals subjected to genetic testing referred to in articles 6 and 7 of the Universal Declaration on the Human Genome and Human Rights, to which Tunisia has acceded and which has been effectively and widely disseminated by the Committee.

51. Furthermore, aware of the complexity, scope and significance of this question, but also of the urgent need to define recognized principles and standards to be adopted at the national level, the National Medical Ethics Committee has decided to dedicate its eighth annual conference, to be held on Friday, 2 April 2004 at Beit El Hikma, to the issue of "Genetic data: scientific context, practical applications and ethical, legal and economic challenges".

52. At the conclusion of its work, the National Medical Ethics Committee intends to submit proposals concerning the protection of genetic data, since that data may have implications for the most private aspects of individuals' lives.

Ukraine

53. In recent years, the conditions have been created in Ukraine for ensuring full cooperation with the international community in studying the ethical, legal, medical and social aspects of the issue of genetic privacy and non-discrimination.

54. The Ministry of Health, the Academy of Medical Science and the National Academy of Science, in particular, are playing an active role in developing that cooperation.

55. Under a joint decree of the Ministry of Health and the Academy of Medical Science, decree No. 313/59 of 1 December 2000 entitled "Further development of medical genetics and bioethics in Ukraine", an interdepartmental coordinating council on the fundamental issues and practical problems of medical genetics was established under the authority of the Presidium of the Academy of Medical Science and the Ministry of Health. The council is made up of scientists in the field of medical genetics who are well known in Ukraine. The decree also provides that, when the state budgets of Ukraine are set for the following years, revenue associated with the funding of measures for the development of medical genetics must be attributed to the list of protected budget items.

56. Since matters of genetic privacy and non-discrimination relate to a wide range of not only medical and biological, but also ethical, legal, social and other issues, the composition of the bioethics committee under the Presidium of the Academy of Medical Science was approved by the aforementioned joint decree of the Ministry of Health and the Academy of Medical Science. Its membership includes Ukrainian scientists well known in the areas of theoretical and clinical medicine.

57. The next step towards creating the legal conditions for the accession of Ukraine to the Convention for the Protection of Human Rights and Dignity of the

Human Being with regard to the Application of Biology and Medicine, and towards initiating cooperation with competent State bodies in foreign countries and with international organizations in relation to the protection of the rights of the human being with regard to the application of biology and medicine, was the establishment of the Bioethics Commission, by decision No. 1677 of the Cabinet of Ministers of 13 December 2001 entitled "Establishment of the Bioethics Commission". The Commission functions as an advisory and consultative organ of the Cabinet of Ministers.

58. The prevention of discrimination on genetic grounds, issues relating to the conduct of genetic testing with due regard for the primacy of human rights, further developments in the area of genetic engineering and hybridoma technology, and the elaboration of techniques to use gene therapy to combat disease — this is far from a complete list of the issues to be dealt with in the area of competence of the aforementioned structures existing in our country in the sphere of bioethics.

59. In implementing the aforementioned measures, Ukraine believes that the standard of bioethics in the country indicates its level of civilization, considering that the world scientific community and international organizations treat bioethics as a matter of the highest priority.

III. Information and comments provided by the United Nations system

Office of the United Nations High Commissioner for Human Rights

60. The Office of the United Nations High Commissioner for Human Rights reported that since its input to the Secretary-General's report of last year a working paper on human rights and the human genome has been submitted to the Subcommission on the Promotion and Protection of Human Rights by its member, Ms. Antoanella-Iulia Motoc (E/CN.4/Sub.2/2003/36). On the basis of the working paper, the Subcommission decided to appoint Ms. Motoc as Special Rapporteur to undertake a study on human rights and the human genome and requested her to submit a preliminary report to the subcommission at its fifty-sixth session and her final report to the Commission at its sixty-first session. The Commission on Human Rights has been requested to approve this decision of the Subcommission at its sixtieth session in 2004.